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Deceased-Donor Organ Transplantation: Knowledge and Attitudes Among Health Care Professionals Managing Critically Ill Patients in Karachi

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Abstract

Objectives: **Adequate knowledge and positive attitudes of health care professionals regarding deceased-donor organ transplants lead to higher donation consent rates. This study assessed the knowledge and attitudes of health care professionals toward this issue in the light of recent organ transplant legislation in Pakistan.**

Materials and Methods: **Health care professionals in critical care areas of 2 hospitals in Karachi were selected (n=243) and asked to complete a questionnaire regarding their knowledge and attitudes toward deceased-donor organ transplants.**

Results: **In all, 58.8% of the participants were physicians and 41.2% were nurses; 91.4% correctly identified brain death; 51.5% expressed support for deceased-donor organ transplants; 56.8% had concerns of religious rulings against deceased organ donation; 67.5% felt that a government body could not run such a system fairly; 56.4% of the respondents would consider receiving a deceased-donor organ if needed, but only 35.3% would donate after their own death. Only 42.7% and 37% were willing to approach patients and families for consent for a deceased-donor organ transplant, respectively. Most of those unwilling felt that the patient could refuse, become upset and aggressive, and lose trust in the health care professionals.**

Conclusions: **Before implementing a deceased-donor organ transplant system in hospitals, health care professionals should attend a training program regarding their concerns. This would increase motivation when approaching patients/patients' families for consent, thus increasing deceased-donor consent rates.**

Key words: *Organ transplant, Critical care, Pakistan*

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Introduction

Organ transplantation is routinely performed worldwide.[1] Advances in immunosuppressant therapy, early detection of graft rejection, and increased confidence in high-risk recipients has radically improved the prognosis for those living with end-stage organ disease.[2] Compared with medical management, organ transplants are not only more effective but also less expensive in the long term, as shown with renal transplantation.[2, 3]

The demand for organs far exceeds the supply and is the main limitation of solid-organ transplantation globally.[4,5] The current state of end-stage organ disease management is grave in Pakistan. The annual incidence of end-stage renal disease in the country is 20 000 to 40 000 per year,[6] whereas the number of live-donor kidney transplants performed is about 400 per year.[7]

Organ donation has 2 potential sources: live and deceased donors. Only in 2009 was a law enacted in Pakistan regulating the latter.[8] While the introduction of this new donor pool should increase organ availability, it may still not match recipient demand. This has already been observed in countries with both live- and deceased-organ donation in practice. According to the United Network for Organ Sharing, 95 000 patients were waitlisted for solid organs in the United States in 2004, but only 27 000 transplants were performed.[9] In India, only 499 deceased-donor transplants including heart, liver, and kidney have been performed since 2000.[10]

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In Pakistan, deceased-donor organ transplantation is under-discussed. With promulgation of the deceased-donor organ transplant act in Pakistan, it is necessary to discuss and identify barriers to this process. A previous study exploring knowledge and attitudes of the general population in Karachi regarding organ donation showed that only a minority was aware that organs can be obtained after brain death, and about 60% were motivated to donate organs. Higher socio-economic strata and higher education correlated with greater knowledge and a positive attitude toward donating. Religious beliefs and doubt of organs being treated respectfully were the most frequent reasons for refraining from live donation.[11]

To improve rates of organ donation, the attitude of health care professionals should be gauged.[9,12] Studies have identified a positive association of increased knowledge, positive attitudes and better training of health care professionals, with deceased-donor transplant rates.[9,13,14] The attitudes of health care specialists of critical care areas (eg, the intensive care unit) are more important considering the large donor pool of brain-dead patients, most of whom do not decide on donating organs during their lifetime. Doctors and nurses in these areas are closer to patients and their families because of their involvement in patient care. This rapport can make requesting for organ donation easier.

Several reasons account for the lack of knowledge, negative attitudes, and insufficient motivation among health care professionals in approaching patients or their families for organ donation. Critical care staff without relevant training feel unprepared to make effective donation requests. Unfortunately, information about organ transplants is not included in most medical and nursing curricula, causing health care workers to be unaware of the modus operandi and communication skills necessary for making these requests.[14] Furthermore, even adequately trained medical staff may be reluctant to broach the subject of transplant with the family owing to strong personal beliefs.

To assess whether a system of deceased-donor organ transplantation can be implemented within an existing infrastructure (the management protocols for health care providers) and social norms in Pakistan, we evaluated the critical care staff's familiarity and comfort with this topic. This study sought to assess the level of knowledge and attitudes regarding deceased-donor transplantation among physicians and nurses managing critical patients. Additionally, factors that could discourage physicians and nurses from approaching patients and families to facilitate organ donation consent were assessed.

Materials and Methods

This was a questionnaire-based cross-sectional study. Participants were selected from Aga Khan University Hospital and Jinnah Postgraduate Medical Center, Karachi. The 2 hospitals were purposely chosen because they are the largest private and public health facilities in Karachi, and represent health care professionals from various parts of the country. Approval to conduct the study was acquired from the Aga Khan University Ethics Review Committee and the medical administration of Jinnah Postgraduate Medical Center, and the protocols conformed with the ethical guidelines of the 1975 Helsinki Declaration. Written, informed consent was obtained from all patients. All data collected were anonymous and coded by serial numbers for confidentiality.

Based on observations elsewhere, we assumed that the largest pool of brain dead patients is in critical care areas. Critical care areas were defined as *the emergency department* and *the intensive care unit*. Participants fulfilling inclusion criteria were selected from these areas by purposive sampling. The study population included interns, residents, nurses, and medical officers who worked and tended to patients hospitalized in these critical care areas. Medical students, nursing students, and physicians who were not posted in these critical care areas were excluded.

Because no similar survey had been conducted in this country, we anticipated that 50% of the subjects would have adequate knowledge and supportive attitudes toward deceased-donor transplants. Using a confidence level of 95%, bound of error 7%, and assuming the population of health care professionals in Karachi catering to these patients to be 50 000, a sample size of 196 was calculated. In all, 20% of the cases were added to account for refusals and dropouts, so the sample size taken was 245.

Questionnaire

The pretested questionnaire included age, sex, profession (nurse or physician), department, and length of experience in critical care. Questions

pertaining to knowledge and opinion about brain death, knowledge, opinions, and concerns regarding transplants had nominal response choices. Questions on the subjects' willingness to approach patients and families to obtain consent for deceased-donor transplants used the Likert scale. Concerns about approaching patients and their families were measured using nominal choice questions.

Data collection and entry

Data were collected during 2 weeks in January 2011. We approached health care professionals who were free from patient duty during morning, afternoon, and evening shifts. We asked if they would fill out a self-administered questionnaire. Data were entered into a database using EpiData 3.1.

Statistical analyses

Statistical analyses were performed with SPSS software (SPSS: An IBM Company, version 17.0, IBM Corporation, Armonk, New York, USA). A knowledge and attitude score was calculated for each participant by combining the scores for all the questions. There were 5 knowledge questions, with a score of 3 or 1 for a correct answer and 0 for incorrect. The maximum knowledge score was 9, with 5 and above interpreted as adequately knowledgeable. There were 11 attitude questions, each with a score of 5 for a positive attitude, 1 for a negative attitude, and 3 for a neutral attitude. The maximum attitude score was 55. Scores higher than 33 were interpreted as an overall positive attitude toward deceased-donor transplant.

The chi-square test of independence and the Mann-Whitney *U* test were used to find significant differences between groups, taking $P < .05$. Spearman's rho was used to determine correlations between ordinal variables.

Results

Demographics

Two hundred forty-three subjects were included in our study, including 100 doctors (41.2%) and 143 nurses (58.8%). The majority of participants were Muslim. Experience in managing critically ill patients varied widely (Table 1).

Knowledge

Two hundred twenty-nine participants (94.2%) knew that organs can be taken out of the body for transplantation. Most (91.4%) also recognized brain death as an irreversible loss of brain functions. Although most respondents (71.6%) felt that deceased-donor transplantation should be legal, only 82 (33.7%) were aware that it is legal in Pakistan. Among our participants, 168 (69.1%) had "adequate knowledge" on deceased-donor transplants and brain death with a knowledge score of 5 out of 9. No significant differences were found between knowledge scores across sex, hospital, profession or by knowing someone who needed an organ. There was no correlation between level of experience in working in critical care units and the knowledge score.

Table 1. Demographics of the Participants

Demographic		Frequency (%)
Number of participants		243
Age		29.4 ± 5.8 years
Marital status	Married	129 (53.1)
	Unmarried	114 (46.9)
Sex	Male	122 (50.2)
	Female	119 (49.8)
Hospital	AKUH	159 (65.4)
	JPMC	84 (34.6)
Religion	Islamic	211 (86.8)
	Christian	18 (7.4)
	Hindu	14 (5.8)
Profession	Nurse	100 (41.2)
	Physician	143 (58.8)
Experience in managing critically ill patients	< 1 Month	34 (14)
	1 Month - 1 year	69 (28.4)
	1 Year - 5 years	65 (26.7)
	> 5 Years	75 (30.9)

Abbreviations: AKUH, Aga Khan University Hospital; JPMC, Jinnah Postgraduate Medical Center

Attitudes

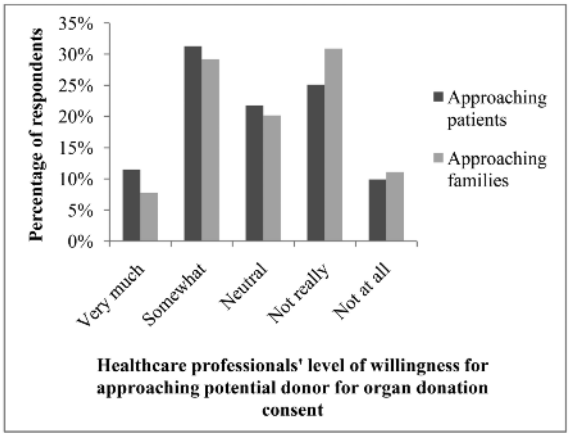
Less than half (45.7%) of the respondents deemed brain death as absolute clinical death. When asked whether they supported live- and deceased-donor organ transplants, 82 (34.0%) and 89 participants (36.6%) were opposed, while 130 (53.9%) and 125 (51.4%) were supportive. Significantly more respondents from the Jinnah Postgraduate Medical Center than Aga Khan University Hospital were supportive of live- and deceased-donor organ transplant ($P = .034$ and $P = .026$).

About one-third of the participants (35.8%) were willing to donate their organs after death, while the rest were unwilling or undecided. In contrast, 137

(56.4%) were ready to receive an organ if necessary. When asked whether immediate relatives (spouse, parent, sibling, or child) should have the authority to give consent for organ donation for a deceased who had never expressed a choice, 118 (48.6%) agreed. When asked if they would be willing to consent for organ donation after a first-degree relative's death, 105 (43.4%) refused. Only 89 participants (36.6%) expressed a willingness to discuss the issue of deceased-donor transplants with their family members. Among these, significantly more participants from the Jinnah Postgraduate Medical Centre than Aga Khan University Hospital were willing to do so (P = .013). Significantly more physicians than nurses were willing to discuss it with family members (P = .043).

When asked if they were willing to approach a patient to obtain consent for donating organs after death (Figure 1), 85 of the participants (35%) were opposed, 53 (21.8%) were neutral, and the rest were willing. When the hypothetical scenario was changed to approaching a brain dead patient's relatives for consent for donating the patient's organs, a larger number – 102 (42%) – were unwilling to do so. Only 54 respondents (22.2%) considered obtaining consent for organ donation as part of their job.

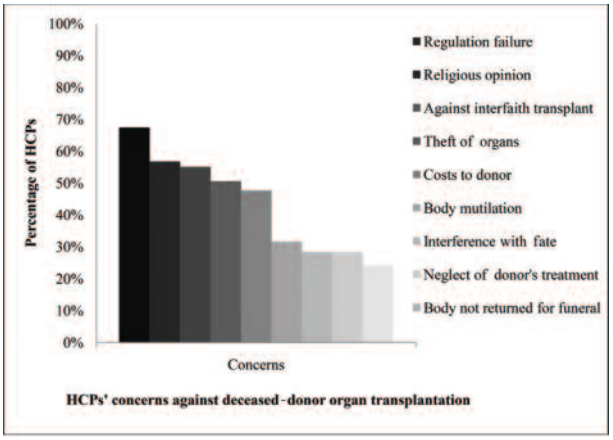
Figure 1. Willingness of Healthcare Professionals To Approach Patients and Families Regarding Consent for Deceased Donor Organ Transplant (n=243)



About half of the participants – 134 (55.1%) – had an attitude score above 33 out of 55 and thus, had an overall positive attitude toward deceased-donor transplant. No significant differences in attitude scores were found regarding sex, hospital, profession, length of experience in critical care, knowledge level, or by knowing or not knowing someone who needed an organ.

Most participants (86.8%) had at least 1 religious concern (Figure 2) regarding deceased-donor transplants, among which 138 (56.8%) were concerned that religious rulings were against it, 161 (66.3%) considered organ procurement to be blasphemous mutilation of the body, and 134 (55.1%) were concerned about transplanting organs to a person of another religion.

Figure 2. Proportion of Healthcare Professionals (HCPs) With Concerns Against Deceased Donor Organ Transplantation (n=243)



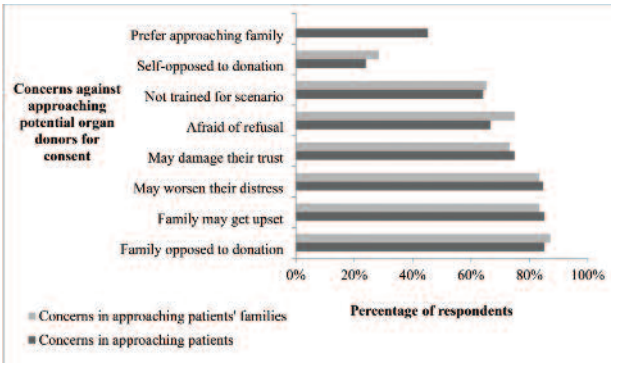
Mistrust of doctors was also high, with 188 respondents (77.4%) having at least 1 related concern: 174 (71.6%) were afraid that treatment for critically ill patients would be compromised because doctors would focus on recovering organs and prematurely withdraw mechanical support, and 123 (50.6%) were concerned about possible illicit procurement of other organs by doctors for profit. One hundred thirty-two (54.3%) were concerned about the funeral and burial of deceased donors, among whom a body with missing parts (98 participants [40.3%]), an unwarranted disfigurement of the body before burial (73 participants [30%]), and the doubtful return of the body to the family for burial (59 participants [24.3%]) were important.

A significant number, 164 participants (67.5%), were concerned that the government's transplant-regulating authority would not be able to run the system fairly and efficiently. Regarding open-ended "other concerns," 2 respondents expressed concern of possibly spreading infectious diseases or malignancy through transplants.

Factors making health care professionals reluctant to obtain consent from patients or families also were assessed (Figure 3). More than 50% of the respondents felt they were not appropriately trained

to obtain consent in such scenarios; feared possible refusal by the patient; were apprehensive of addressing a patient opposed to deceased-donor organ transplantation; and were afraid of damaging the patient's trust, worsening their distress, and causing them to become aggressive. One hundred ten health care professionals (45.3%) preferred to approach the family for consent rather than a patient. Similar concerns were found regarding approaching the relatives of a brain-dead patient (Figure 3). More nurses than physicians were concerned about damaging the trust of the patient and family (P = .001 and P = .015). Respondents not acquainted with a patient requiring an organ had more concerns than respondents who knew someone in need of an organ (P =.030).

Figure 3. Concerns of the Respondents in Approaching the Patient and Family for Consent for Organ Donation After Death (n=242)



Discussion

Pakistan is burdened by a high recipient demand for donor organs. Because of the recently passed law, we found a reasonable level of knowledge of brain death among health care professionals in our sample. However, participants lacked a positive attitude and motivation when approaching patients and families for consent for donation of organs after a patient's demise.

More than 90% of our participants were correct regarding the contemporary definition of brain death. This is remarkably higher than that reported by Sheerani and associates[15] in 2008 (46%). However, they assessed knowledge of brain death more comprehensively than this study did. A study of critical care nurses and physicians in Karachi in 2008 reported that 69% of the participants had adequate knowledge.[16] The knowledge level in our study did not tally with the respondents' attitude toward brain death. Surprisingly, 43.2% disagreed with the global consensus that brain death is equivalent to absolute clinical death. Sheerani and associates[15] found that 26% participants equated turning off the ventilator in a brain-dead patient with euthanasia. Literature from neighboring Iran, which has an existing transplant system, also reports significant misinterpretation of the concept of brain death.[17]

Participants in our study with adequate knowledge of deceased-donor transplantation totaled 69.1%. This was higher than the level of knowledge previously reported for the general population.[11] Being comparable to the knowledge rate reported elsewhere,[9, 12] we could safely assume that Pakistan is not behind other nations regarding its health care professionals' awareness of organ donation. Although a positive relation between the level of medical education and the extent of knowledge on deceased-donor transplants has been reported by Schaeffner and associates,[12] no such correlation was found in our study. This may be a sign that a sufficient level of knowledge exists at all levels of experience, or, that health care professionals' level of knowledge regarding organ donation does not expand through their careers. Schaeffner and associates[12] included preclinical students with a lower knowledge level, which could have exaggerated the trend.

Although more than half of our respondents claimed to support organ donation, only 35% would donate their own organs after death, and only 32.5% would donate a family member's organs. Remarkably, this rate of willingness to donate among health care professionals was lower than the rate determined for the general population in Karachi (62%).[11] However, a higher number of our study's participants (56%) would receive an organ if their life depended on it. The approximately 20% of subjects who would accept an organ, but not donate, can be categorized as "free riders"—persons refusing to donate organs but having equal access to receiving a transplant.[18] This problem will arise out of the opting-in system that Pakistan is adopting. Ethically, these persons cannot be denied a transplant if they need one, but it seems unfair to those who donate.

In our study, willingness to donate organs was not associated with duration of experience in critical care areas. This contrasts findings of a study from Brazil that showed that increased years of medical practice had a negative effect on willingness to donate organs.[13] We also found no significant difference between

nurses and physicians in the willingness to donate organs, as was reported from Turkey.[9]

Religious decrees against deceased-donor transplants concerned more than half of our participants; Shabanzadeh and associates[17] reported similar findings. A study in India with mostly Christian respondents reported 89% of the doctors being willing to donate their own organs, and 69% as willing to donate organs of family members.[10] This difference in religious background may underlie differences in willingness to donate.

The main objection of religion to deceased-donor transplants is that it violates the sanctity of the human body. However, Islamic jurisprudence is flexible when society's welfare is at stake.[19,20] In these cases, the rights of the living supersede those of the dead, because the benefit accrued in the outcome is greater than the harm of bodily disrespect for the deceased donor. The Council of the Islamic Fiqh Academy of the Muslim World League (Makkah, Saudi Arabia) in 1985, and the Council of the Islamic Fiqh Academy of the Organization of Islamic Conference (Jeddah, Saudi Arabia) in 1988 have concluded that it is permissible within Islamic law (Shari'ah) to remove organs from the deceased.[19,20]

In a society where bureaucracy is inefficient,[21] the public is generally averse to anything associated with "government." Most study participants doubted whether the organ transplant system can be implemented fairly, and policymakers and government officials must work hard to allay such fears among the medical community.

Despite adequate knowledge and even a supportive attitude toward transplants, physicians and nurses can be reluctant to approach potential donors to obtain consent. As evidence, about half of our study's respondents felt that obtaining consent for donation should be the transplant team's job rather than theirs. Their reluctance toward obtaining consent was mainly because of concerns of worsening the patient's or family's distress and losing their trust. About 65% also were concerned regarding their lack of training for these scenarios. Thus, any efforts to maximize deceased organ donation rates must train health care teams to communicate with patients and handling potentially "difficult" patients or families effectively. A German study reported only 8% of physicians felt ready to approach relatives of potential organ donors.[12]

Nurses interacting closely with patients and their families develop emotional attachments to them and show "protective behaviors."[22] We found significantly more nurses than physicians being afraid to damage the families' trust by asking for consent for organ donation. Training circumvents such protection behavior and makes nurses more comfortable in their approach for consent.

A significant positive relation has been reported between knowledge on deceased-donor transplantation and attitude toward the issue.[9] In our study, there was no effect of knowledge of organ transplantation or familiarity with an organ recipient on the attitude. We also found that nurses and physicians strongly felt the need for relevant training in health care curricula and implementation of educational programs before promulgation of deceased-donor organ transplant in this nation. We know from Aghayan and associates[23] that training workshops improve knowledge, and, in turn, the donation rate. Evanisko and colleagues[14] also showed that training on organ donation, particularly on making requests for donation, improves the ability and readiness of critical care staff in handling potential donors.

Disappointingly, less than a third of the participants were aware of legislation on deceased-donor organ transplantation in the country despite more than a year having passed since the ordinance. The government's move to enact the *Transplantation of Human Organs and Tissue Ordinance* in 2009[8] aimed at rushing in deceased-donor organ transplants, but the years after ordinance have seen little effort in training doctors and nurses and cultivating better attitudes. Education and motivation of physicians/nurses are as important as legislative efforts or establishing professional teams for coordinating organ transplant.

Based on the findings from our survey, we propose nationwide programs to inform both the medical community and the public regarding organ transplantation. Also, before implementing the law, hospitals must organize training sessions to teach health care workers who must obtain consent for deceased-donor organ transplant.

Limitations

Only 2 tertiary care centers were surveyed in our study. Although these were large public and private institutions, the results may not necessarily be

generalized to other health care settings in the country. The participants may have felt pressured to support transplants in an environment gearing up to implement the transplant system, thus overstating their positive attitude. Further, although prior literature influenced our analysis, adequacy in knowledge and attitude scores in the study were determined arbitrarily. Thus, our estimates of knowledge and attitude are not absolute.

Conclusions

This study demonstrated that only half of the sample health care professionals expressed support for deceased-donor organ transplants, an even lower number was willing to approach patients and their families to obtain consent, and only one-third was willing to donate their own and their family members' organs. Religious rulings, mistrust of doctors, and mistrust of a government regulating body were important concerns among participants regarding a future transplant system. Despite 69.1% of the participants having adequate knowledge of organ transplantation, only 42.8% and 37.0% were willing to approach potential donors and their families. The most important factor for those unwilling was fear of upsetting the patients or their families. We recommend that before implementing the deceased-donor organ transplant system, health care staff should go through a training program that addresses these concerns, making them comfortable with approaching potential donors. This will increase their motivation in approaching patients/patients' families for consent, and will consequentially increase deceased-donor organ procurement rates.

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